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Inklusive Forschung

Gemeinsam mit Menschen mit Lernschwierigkeiten forschen

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Buchner / Koenig / Schuppener

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Val Williams

Being a researcher with intellectual disabilities: the hallmarks of inclusive research in action

Introduction

Inclusive research is a broad church, as will have been seen from the various examples and papers in this book. The current chapter stems principally from work done at Norah Fry Research Centre at the University of Bristol in the UK, where inclusive research has been one of the hallmarks, and where from the outset, it has been acknowledged that there are many different models and approaches (Minkes et al. 1995; Ward & Simons 1998; Rodgers 1998; Williams 1999; Marriott & Williams 2010) distinguished largely by the positioning of people with intellectual disabilities in the design of the project. The very term 'inclusive' research (Walmsley 2001) subsequently gave us a way of conceptualising this spectrum of approaches, ranging from the more purely 'emancipatory' research advocated by Oliver (1992) where disabled people are in control, to 'participatory' research (Zarb 1992) where disabled people may be recruited into studies led by academics. However, all of these approaches aim fundamentally to trouble and overturn the more traditional social relations of research production, in Oliver's 1992 terminology. They all aim to introduce the voices of people with intellectual disabilities, as active agents in shaping their own lives and their own knowledge. This chapter therefore aims to showcase some of those voices, and to show how we can learn more about what constitutes inclusive research by analysing the fine detail of the interactions that take place during the conduct of research studies. A fuller explanation and exposition of this approach is given in Williams (2011); here I hope to give just a taster, which I trust will enable readers to be spectators to the words, and research interactions, which include people with intellectual disabilities.

The notion of inclusive research has attracted many helpful critiques. For instance, Chappell, (2000) and Walmsley (2001) are classic sources that have stimulated debate. Without wishing to re-iterate here the many tensions that lie at the heart of inclusive research, I will focus here on a couple of points only. First there

have long been concerns about the sheer cognitive ability required to consider abstractions, to form theory or to analyse the meaning of research data (Chappell 2000). Redley & Weinberg (2007) showed how people with ID were frequently more comfortable talking about their own, personal affairs, rather than forming political or conceptual conclusions. Having considered that point in relation to my own data, I have come to the conclusion that this link between the personal and political is one of the hallmarks of inclusive research, and I will try to illustrate what I mean by that at the start of this chapter.

Linked to the worries about the ability of researchers with ID to form abstractions, there have also been many debates about the 'reality' of autonomy and ownership in inclusive research. Since emancipatory research has been associated with the autonomous voice of a disabled people's collective, many authors dispute whether this type of autonomy is ever possible with people with ID (Bigby et al. 2014; Nind & Vinha 2013), and whether the unseen influence of non-disabled or academic supporters is taking over from the voices of people with ID. In order to develop this point more deeply, we need to consider the distinction between the notion of individual autonomy and relational models of autonomy, where people are recognised as being interdependent (Smith 2013; Kittay 2011). This distinction resonates with the idea of independent living, one of the conceptual planks put forward by the disabled people's movement across Europe (Morris 2003). Independence does not mean doing everything for oneself, but rather being in control of the supports one has in life. Much depends therefore on the relationship between the disabled person and those around them, and how that plays itself out in everyday interactions. That point is also directly relevant for inclusive research contexts, and is one that I hope to illustrate through data taken from two projects. The first study was carried out by and with a small group of people with ID in 1998; I was a voluntary supporter, and I recorded virtually everything that was going on during our meetings and data collection. The group published their own version of their findings (Palmer et al. 1998), but subsequently allowed me to use my recordings for my doctoral dissertation in 2002 (Williams 1999; 2002), which sought to characterise inclusive research as a social activity. The second project I draw on in this chapter is described in Williams et al. (2009a; b; c) and was a fully funded, national research study carried out in partnership with a self-advocacy organisation, looking at the interactions between support workers (personal assistants) and people with ID. Two people with ID were employed as researchers, and I was the lead researcher and advisor to the study. Together, we collected some twenty hours of video data by direct observations of activities carried out by our participants. The researchers with ID in this project thus became directly involved in analysis of the interactional data, most of which was about one-one support practices, and produced a training pack and DVD as a practical output (Ponting et al. 2010). For the purposes of the current chapter, I will focus on the study as

an example of inclusive research, showing how it contrasted and added to the interactional knowledge from the earlier study in 1998.

1 Personal experience made visible in research contexts

The following conversation took place during a focus group discussion in the 1998 study. Mark, Angela and Ian are all members of the research group, and Darren is one of the participants in a self-advocacy group which they visited as part of their data collection. The question that had given rise to this extract was 'What services or transport do you go on?' and there had just been some discussion about the needs for access to minibus transport, when Darren, the only wheelchair user in the room, spoke up.

Extract 1

1. Darren	I like to say that we should be able – not we – I or people like me that
2.	are in wheelchairs? (pause) should be able to go out anywhere.
3. Mark	Yes
4. Darren	If we got a life (pause) no?
5. Mark	I see your point there
6. Darren	But can you tell me why not?
7. Mark	Uuhh
8. Darren	No you can't.
9. Angela	Hard question that to answer isn't it, that one
10. Ian	Yeah
11. Darren	Aahhh (scowls)

(Adapted transcript of Extract 9.1, Williams 2011, 129)

There is no space here for a full description of conversation analysis (CA) which is the basis of the methodology I used in analysing data in Williams (2011). There are many other textbooks, including Woffitt (2005) and ten Have (2007). For now, the important points are simply that CA examines what actually happens, and takes an interest in how people's talk is organised in live interaction – how one turn links with another, and is shaped by what has *just happened* in the talk. By taking this perspective, we can see how people do things with their utterances, how for instance in Extract 1 Darren takes up a position as spokesperson for wheelchair users, how he is supported by Mark, Angela and Ian, and how they in turn use their turns to make his contribution relevant to the group discussion which they were leading.

Darren starts his first turn with a quick collection of pronouns, shifting from 'I' to 'we' to 'people like me', both claiming his own personal stake in what he is about to say, but simultaneously shifting to the collective voice of 'we'. He is not only speaking on his own behalf, but quite explicitly here on behalf of other people who use wheelchairs.

In focus group discussions in traditional research contexts, one might expect the questions and the agenda of the discussion to be broadly the domain of the researcher or researchers, while those taking part in the focus group are considered as 'participants'. While the four members of the research group had in fact fixed the visit, and had arrived with their own questions, the data above immediately raises the question of who was the researcher in this context. It ought to be noted in this data that I, as a novice academic researcher and a supporter, was also present during the discussion, as was also a support worker from the self-advocacy setting. We were both silent during this first extract, and the people with ID from both groups sorted out for themselves how they were going to shape the discussion. Darren's challenge in Line 4 („If we got a life, no?") could be heard as a way of splitting the group into people like himself who used wheelchairs, and all the others who did not. At the same time, he is doing what one might expect a researcher to do (Silverman 1973) by asking a question, demanding an answer. Wisely, Mark as one of the research group members, simply agrees and validates Darren's position with „I see your point there", although Darren then persists in his demand for an explanation, as if the research group members could be held responsible for the wrongs done to people with physical impairments. In CA, this type of identity work can be analysed, and it becomes apparent how the identities people take up in talk shift on a moment-by-moment basis. At one point, Mark is positioned as a non-wheelchair user, at the next he is making relevant his right to validate what people have said in the research. This is subtle work. Not only are all the speakers here orienting to the personal as a 'political' act, but they are also creating a focus group discussion by performing the interactional work required by researchers.

2 Joint work in building up a political argument

Following on from Extract 1, Darren continues with some more rhetorical work, relating the wider arguments to his own position, demonstrating some emotion about his frustration, and challenging the research group to offer him solutions. A few turns later, the following occurs:

Extract 2

1. Angela	Why don't you write to the – why don't you write to the prime minister and
2.	ask him for some help and advice and see if you can get some money for
3.	doing it right?
4. Darren	But if I write to the prime minister –
5. Angela	You might get something out of it
6. Darren	I'm just going to get my letter I send to him – it's going to be ripped up
7.	and thrown away
8. Angela	Don't think so
9. Darren	Yeah
10. Mark	Not if you explain what you want

(Adapted transcript of Extract 9.2, Williams 2011, 131)

One of the basic analytical tools of CA is the 'two-part sequence' which routinely characterises conversation. It can best be understood as the question-answer routine which underlies Extract 1. When someone has answered a question, or produced a responsive utterance, that provides a possible point at which matters could be concluded. Maybe someone else could come in at that point, the topic could be altered, or in fact the discussion could be shut down. For instance, Angela's question at lines 1-3 could have simply been answered by Darren as 'Yes that's a good idea, thank you'. The discussion may then have been moved on, perhaps with another question from the research group. However, each time he has a turn in the conversation, Darren keeps the floor by adding something that challenges what Angela has asked him or has suggested. Despite her open disagreement at line 8 („don't think so") Darren maintains his own counter argument that all action is useless, that politicians will not listen, and that he does not have an answer. By contrast, the suggestions made by Mark and Angela position Darren as an active agent, someone who could make a difference in his own life by taking action, writing a letter and explaining what he wants.

This is part of a much longer sequence in which suggestions, challenges and counter-suggestions are made by members of both groups, and in which Darren is seen quite expertly to morph between a self-portrayal as passive and hopeless, into a slightly comedic personality able to laugh at himself. In doing this, he becomes the lead voice in this part of the data, maybe in some respects putting research group members on the back foot. However, they rise to this challenge, and what happens could be described as a lengthy sequence of advocacy-in-action, with group members all joining forces to explore possible solutions to the problems faced by wheelchair users.

As I reflected on and analysed this data, I could see how one of the distinctive features of inclusive research was emerging. When the researcher is an academic or non-disabled researcher, the participant(s) can certainly have a voice. However, the power to ask questions and define what is relevant to the purpose of the research, remains with the interviewer or researcher. That asymmetry of interactional rights therefore characterises most research data, and in transcribing traditional qualitative research, we quite often ignore what the researcher is saying or asking, implying that all that matters is the voice of the participant. By contrast, what is happening in Extracts 1 and 2 is very much joint work, where both researchers and researched join forces to develop their own solutions, almost as a collective. The position of researcher thus becomes quite a blurred one, with the researchers struggling at times to answer the questions posed by Darren, who was in traditional terms a 'research participant'. At other points in these focus group discussions, research group members pitched in to the discussion, in effect answering their own questions or contributing their own experience to the data. All of that might be considered by some critics as biased or non-robust research. However, through

an interactional lens, I could see how the social activity of inclusive research was emerging as quite distinctive. If people with ID are doing research because they are experts by experience, then they need to bring that experience to bear in jointly producing data. Maybe in fact that joint work is one of the key, defining features of inclusive research.

3 Behind the scenes in inclusive research

The data in Extracts 1 and 2 are what Goffman (1959) termed 'front stage' events. However, in both projects I explore here, I also had recordings of what was happening 'backstage'. These are important to look at, since some of the concerns about inclusive research focus precisely on what is happening behind the scenes, where the reader generally does not have access to the interactional dynamics and the roles taken up by supporters or non-disabled researchers. In order to give a taster of this data, I turn to the second study (Williams et al. 2009a) in which the researchers with ID were helping to analyse video data. The results of their analysis can be seen on our training DVD (Ponting et al. 2010). Naturally these were the 'end result', performed for camera; nevertheless, they did have a basis in the insights and discussions we pursued during the course of the project, and Extract 3 is taken from one of those discussions which was about a video we had filmed with a support worker and a person with autism and ID.

Extract 3

1. Val	Do you think when people are chatting about social things like Ellie does
2.	at the beginning, it's part of being friendly and being relaxed with your
3.	support worker?
4. Lisa	Yes
5. Kerrie	Ye-ah
6. Val	mm hm?
7. Kerrie	But –
8. Lisa	There again it depends, it depends who you – your support worker is
9. Val	Mm-hm
10. Kerrie	The house have always – have always said to me, there's a time and a place
11.	for something.

(Adapted transcript of Extract 12.3, Williams 2011, 176)

In this extract, we had been watching together one of the videos we had made, where a person with learning disabilities, called by the pseudonym here of 'Ellie' was being supported to plan her shopping list. This short extract shows how I take quite a lead role in defining and suggesting what we should talk about – namely, the social chat that Ellie had initiated at the start of our video. Although I frame my turn in lines 1-3 as a question, this is very much a closed question, to which I already have an answer. In fact, I offer Lisa and Kerrie the option of saying 'yes' or

'no', and my question is heavily weighted towards a 'yes' answer with a suggestion of why social chat might be something that helps you to be 'friendly and relaxed' with your support worker. Lisa does what is called in CA a 'preferred response' by answering yes, but Kerrie is more equivocal with a long drawn-out 'yeeah', and I take this up by asking her to expand with my 'mm-hm?' at line 6. This seems to have the effect of offering both Lisa and Kerrie the chance to come in with something new, something they want to add to the discussion. In fact, Lisa's point seems to be oriented towards the differences between various support workers, while Kerrie moves to her first step in a more extended argument about the role of support workers, to focus and advise people like herself. Her use of the word 'house' signifies the staff members who work in her house, and perhaps comes over as quite an institutional word, something that positions her support workers as being a very part of the place she lives.

Much could be said even about this short extract. For the moment, I simply want to point out how the sequencing of turns in a conversation like this really does matter, since it gives a way in to analyse how each person takes the previous utterance. Although I could be heard to direct and initiate the discussion, both Lisa and Kerrie quickly assumed their rights to challenge and expand on what I have said. Line 6 (mm-hm?) is thus key to what happens next. By listening carefully and encouraging Kerrie to come back in with what she wants to say, I am able to explore more of the insights both Kerrie and Lisa are offering. The same extract then continues in an even more interesting way.

Extract 4

1. Val	mm-hm?
2. Kerrie	[and if you –
3. Lisa	[have I got to sign here Val? (picks up a form she had been filling in)
4. Val	Yeah let's just leave it for a minute, is that alright?
5.	[Put it up there –
6. Kerrie	[If you er are trying to concentrate on something, then it's best to focus your
7.	mind on just that one thing, otherwise you might forget something or your
8.	brain might wander off on something.
9. Lisa	I agree with Kerrie
10. Val	Yes and that's exactly what I did just now wasn't it?
11. Lisa	Yes
12. Kerrie	Yeah
13. Val	(laughter)

Just as Kerrie is about to launch into her explanation of how support workers can help you to 'focus your mind', Lisa interrupts by picking up a form she had been filling in, and asking me about where she needed to sign it. The square brackets at the start of lines 2 and 3 mark where one person's speech overlaps or interrupts another's. Lisa has thus broken in to the flow of the discussion, with something

which I deem to be irrelevant, and I ask her at line 4 to leave the form until later. This gives Kerrie the floor to continue with her exposition of how she (and others) need to focus on one thing at a time, with the implication that the social chat at the start of our DVD may have been irrelevant and distracting for the participant, Ellie.

This is interesting at so many levels. First, it should be noted that both researchers with ID are concurring with a point that opposed my own preferred interpretation of the video – i.e. that it is good to be 'friendly and relaxed' with your support worker. Secondly, the argument drawn on by Kerrie is essentially an impairment specific one, related to the notion of what it is like to be a person with ID, who actually does have cognitive difficulties. She is very much bringing her own experience to bear on the analysis we carried out. Thirdly, however, the interruption by Lisa occasions a wholly directive utterance from me, when I tell her to leave that till later. I am assuming here the right to determine what is actually relevant, and what is not, at this point in our discussion, and no-one disputes that right – it is simply accepted that this is my role. In effect, I am mirroring unintentionally the role of a support worker who may direct, guide and focus a discussion – and I do in fact remark on that at line 8, pointing out the coincidence to Kerrie and Lisa: „Yes and that's exactly what I did just now wasn't it?" This occasions a good deal of laughter, as we all orient to the way in which we ourselves are re-enacting the social practice under discussion.

Not only do extracts like this give direct evidence of the analysis that goes on behind the scenes, but they allow us to see more exactly the strategies and patterns of talk that can occur between researchers with ID and an academic supporter. Producing knowledge about research can be done in situ as seen in Extracts 1 and 2, but it can also be done at the stage of analysis. On both occasions, it could be said to be a joint production, involving more than one person. However, the backstage talk gives us more of a handle on the influence, role and strategies at the disposal of a research supporter. I should emphasise that the discussion in Extracts 3 and 4 was not the end point of the analysis, and my own role in this second project was quite different from that in the first. Kerrie and Lisa both became very directly involved in discussion, and some very detailed 'noticing' about what went on in our video data. However, I still had the right to take away the data, using their insights to carry out a more detailed conversation analysis of what was going on, returning to them with my analysis and discussing with them what they wished to include in their own training pack.

Joint, collaborative work was thus the hallmark of both the projects discussed in this chapter, and I will explore further the shape this took in the following series of extracts, which start from the preparation stage of the first study.

4 Backstage work to prepare research questions

In Extracts 1 and 2, I gave a short glimpse of some of the data produced in focus groups by the researchers in the first study (Palmer et al. 1998; Williams 2002). Their research came about largely because they were keen to find out, in their own words:

> *"whether other people with learning difficulties are hitting their head against a brick wall like we are".*

In other words, they wished expressly to learn how their own experiences matched up to those of others with ID, and they chose to do this by visiting self-advocacy groups to pose their questions and record the answers. Even in their initial conception of the aim of their project, then, they encapsulated the shared identity they assumed with their participants, who were seen as 'other people with learning difficulties', and who might have a shared experience that they could understand. This shared identity became a very interesting point, since their first research question was one about the problem of labelling, and gave rise to some interactional trouble on the very first time that they tried it out. I will briefly trace here the pre-history of that question, in our preparation work behind the scenes.

Extract 5

1. Val	Right so the first one – what was that question then Angela? What do
2.	people- (standing at flipchart, writing up people's words, as I turn to
3.	look at them)
4. Angela	What – what does your friend think about horrible things?
5. Val	What do you think about – (pause) well if you asked somebody what
6.	do you think about horrible things, do you think they'd understand?
7. Angela	What do your friends think about YOU being called names – you know
8.	being labelled and being called nasty things you know
	(several turns here, relating to who are the people being labelled)
9. Val	So I'll just put "people" for the minute, shall I? People being labelled?
10. Angela	Your best friend. What do they think about you –
11. Val	OK, are there other things –
12. Harry	Well maybe I mean, that could be something like people with learning
13.	difficulties
14. Angela	Don't like that word
15. Mark	Yeah
16. Ian	Don't Harry, don't keep on about it, I don't like it.

(Adapted transcript of Extract 13.2, Williams 2011, 188)

My own role in helping the group members to formulate their question is certainly of interest here. I am standing up, writing up their words on a flipchart, very much something one might expect of a teacher, assuming final control over how their own words were heard and recorded. Nevertheless, Angela persists in trying

to express what she wants to get out of the question, returning time and again to 'friends'. My own attention is on attempting to formulate a question which the group could ask at their focus groups, while her attention is clearly more on the notion of how she herself sees the people they might meet during the focus groups – people who are peers, friends, or 'people like me'. There is certainly some confusion of purpose here. However, what does emerge clearly is that the actual mention of the term 'learning difficulties' occasions reactions of hurt and sensitivity. Angela, Ian and Mark all align with the position that they do not like the word, and do not want therefore to mention it in their focus group question. The question thus eventually becomes maximally ambiguous in its reference, and is worded as:

"What do you think about people being labelled?"

Given that these group members were first-time researchers, at this point without any direct experience, their sensitivity in prefiguring and thinking through the ethics of their research questions took my breath away. At another point in the same meeting, for instance, Mark vetoed a question about people being bullied, saying 'it might offend the person you ask the question to, and it might give people bad reactions – it might cause an upset between the person you're asking the question to and also who's asking the question' (Williams 2011, 189). No wonder then that we were all pent up with excitement when we set out to conduct our first focus group.

5 Talking about labelling and identity in the focus groups

The very first focus group session started with some preliminaries, and indeed with the type of 'social chat' Kerrie and Lisa were later to suggest may distract people (see Extracts 3 and 4 above). Nevertheless, we did settle down comfortably, with some eleven people around a table, Mark at the head of the table, and one supporter from the self-advocacy group also sitting at the table. I myself was also there, with the video camera to hand, as Mark started on the first question, looking down and reading it authoritatively from his written sheet.

Extract 6

1. Mark	We're going to ask um yourself, what you think of the questions we thought.
2.	The first one (pause) "What do you think about people being labelled?" That's
3.	to all of you.
4.	(Mark looks round at everyone, smiles, and makes a sweeping gesture with
5.	one hand)
6. Jon	Well –
7. Darren	What – sorry, you go –
8. Jon	In what sort of way? Labelled in what sort of way?

9. Mark	Er, what do you think about people being labelled, being um like being – um,
10.	like, like with a learning difficulty?
11. Will	Like-like us you mean?
12. Mark	No, like like learning dis-disability
13. Will	Oooh.

(Adapted transcript of Extract 13.4, Williams, 2011, 190)

Mark offers the first question to anyone in the group who wishes to answer it, and there is some slight trouble at the beginning about who should answer, with Jon and Darren both coming in. Darren then cedes the floor to Jon, and instead of giving his own answer to Mark's question, he does what we call in CA very much a 'dispreferred action' at line 8, by questioning the basis of the question: "In what sort of way? Labelled in what sort of way?" Despite the careful preparation to avoid being specific about the word 'learning difficulty', as soon as the question is posed *in situ*, it causes an interactional problem! Mark bravely carries on, albeit with a degree of hesitation and hedging at lines 9-10, where he still trying to avoid the word he thought might be offensive, eventually giving in and mentioning it. However, notice that he has still not actually inferred that the group members themselves have a learning difficulty. He is asking them for their opinion (what they think) about "people being labelled…. with a learning difficulty".

As soon as this question had been more explicitly delineated by Mark, the very next person to speak gets straight to the heart of the identity issue: 'Like – like us you mean?'. This was exactly what Mark and the others had been trying to avoid! In these four words, William cuts straight to the issue of membership categories, effectively asking Mark not just what the question meant, but 'in what category (or identity) should I be responding?' The video record shows here how much trouble this created, particularly for Mark, who was taking on the responsibility for starting off the discussion. Shortly after Extract 6, he turns directly around to look at me, with an expression of panic on his face. I turn off the video camera for a moment, to reassure and guide him, before the discussion picked up again. It was interesting then to see how all the people present in the room started to take responsibility for pulling the discussion back into line, with Jon picking up on the term 'learning disability' that Mark had introduced in line 12. At that time, in the UK, the term 'learning disability' had only just started to be the current, official terminology for people with intellectual disabilities, although self-advocates then (as now) generally used the alternative word 'learning difficulty'. They are both so similar in the English language that it is quite easy to slip unintentionally from one to the other, but Jon starts to relate the terminology to the notion that it has recently been dictated by the UK government. In some respects, Jon's talk serves to depersonalize the issue, to move it onto the choice of word, rather than the actual identity of the self-advocacy group members. However, Darren then comes back in a few lines later:

Extract 7

1. Darren	You don't need to know that (to Jon)
2. Sheila	We do
3. Mark	I think - we (pause)
4. Will	We've gone off the wrong track now haven't we?
5. Mark	Yeah, we have actually

There is a large CA literature about the topic of 'repair'. When there is a misunderstanding, or when someone fails to hear another person's utterance, then they generally initiate a repair turn, in which they seek clarification. In the present case, there has been some overall misunderstanding, both of the original question asked by Mark, and also of the purpose and relevance of the subsequent discussion. William's phrase: 'We've gone off the wrong track' rather neatly sums up the way in which a conversation can stray from the 'right track', which was one presumably dictated by the overall plan created by Mark and the research group. In this way, then, all the group members (both the research group and the self-advocates they visited) were taking some joint responsibility for re-directing the discussion, and indeed, a few turns later, they did manage that task successfully, through some overt body language which seemed to melt the ice, and make it clear that both Mark and Jon were in fact people who were oppressed by the terminology used about them. If inclusive research is premised on the fact that the researchers share an identity with their participants, then this particular data was able to reveal how that peer identity played itself out in action. As it turned out, matters were not always easy; however, the smooth flow of the subsequent discussion appeared very much to depend on that recognition that researcher and researched had both shared experiences and identity. Inclusive research, in other words, can go into sensitive topics with a delicacy that might be very difficult for a non-disabled researcher, and I will discuss this further in my concluding comments.

6 Discussion: what does this all mean for inclusive research?

In the fifteen or more years since I started working with Mark and the other group members to support them in carrying out their research, much has changed and moved on in inclusive research. The importance of grounding this type of research in a self-advocacy context, within organisations run by people with intellectual disabilities, cannot be emphasised enough (see also Priestley et al. 2010). In fact, in the UK, much of the most exciting inclusive research is carried out by self-advocacy group members, for instance in Carlisle People First and Dorset People First. Sometimes, those organizations have formed partnerships with the academy, as in other work in which I have been involved (Gramlich et al. 2002; Tarleton et al. 2004). In fact, the study in which Kerrie Ford and Lisa Ponting worked as researchers was owned and managed by a 'centre for independent living', part of

the disabled people's movement. That positioning was important as a backdrop to the detailed interactions I have discussed in this chapter, since it enabled inclusive research to be part of the wider movement towards independent living and disability rights. However, in all these contexts, it remains important that we are vigilant about examining the *style* of interaction, the talk that goes on backstage, as well as in the public activities of the research. Non-disabled supporters, as well as researchers and academics, are becoming more and more associated with each other, with several self-advocacy group supporters becoming qualified in research through an MSc course set up at the University of Bristol. At the same time, other supporters have become academics themselves, blurring and questioning the role definitions of 'supporter' and 'researcher'. That frankly has to be a good thing; the blurring and undermining of our assumptions of who is who in research is a way of making us question what is happening, allowing us to see inclusive research as emerging in its own right as a myriad of different, but fresh, ways of producing knowledge.

In this chapter, some of the characteristics of inclusive research have been explored in the context of the interactional dynamics of two particular projects, set up in different ways and at different points in time. However, they did have much in common. We have seen for instance, how being a researcher with intellectual disabilities enabled people to take control of the interaction. Instead of being the respondent, as is most often the case amongst people with ID, Mark and the other researchers were stepping into the role of 'researcher' precisely by taking on the interactional rights to ask questions, determine the agenda, and decide what counted as relevant data. These are powerful things to do for people whose lives and identities may have been defined by being treated as interactionally incompetent (Antaki et al. 2007; Williams et al. 2009b). Therefore the first and defining hallmark of inclusive research has to be that achievement of interactional power, where people with ID are taking on roles traditionally denied to them.

However, the data explored in this chapter takes us further than that. If being a researcher with ID simply means becoming skilled in the art of questioning and controlling a focus group, then certainly Mark and his colleagues were already demonstrating their skills in 1997. Yet one could then ask whether they really were typical of people with intellectual disabilities – would those skills not simply be too much to ask of most of their peers? In fact, the group of four who undertook that project were all very different in their skills and communication abilities, sharing simply the enthusiasm and curiosity necessary to fuel them through that project. That is perhaps not the point, though. Inclusive research has to be offering something distinctive, something more than simply 'aping' the skills of academic researchers. I would argue for instance that Kerrie and Lisa showed us in Extracts 3 and 4 how their own personal experience really mattered. It was by reflecting on her own experience that Kerrie was able to challenge my interpretation of the

video we were analysing. In both the projects under the spotlight here, there was an element of sharing, joint construction of meaning, and in fact, open discussion about meanings by all parties during the actual collection of data.

Identity therefore threads through as a key topic in this chapter, and in all the inclusive work I have been involved in. The questions and rich discussion that followed Mark's question about labelling would simply not have happened in a traditional academic research context. In fact, academic researchers such as Todd and Shearn (1995) who tackled the same topics about labelling and self-identity, were often met with silence or avoidance, which they interpreted as a lack of knowledge amongst people with ID about their own label. Rapley et al. (1998) subsequently suggested that, from an interactional point of view, the bald direct questions used in Todd and Shearn's research could be heard as downright rude (Williams 2011, 189). By contrast, the delicacy and forethought put into constructing a non-offensive question were quite remarkable in Extract 5, where Mark and his colleagues were able to explore identity and labelling in their focus group discussions, in ways that brought into play their own shared identity. Being a person with an ID really matters in this context, and that point is perhaps nowhere more eloquently stated than by Stacey Gramlich in the inclusive project about direct payments in which he was involved:

> *"Having a learning difficulty is not something to be ashamed about. I am proud of who I am. If I resented it, then I would be a wreck. Some people may think that people with learning difficulties cannot be researchers, but we know that we can do it. In a lot of research, we are the exhibits. But now we are not just part of the picture – we are the artists of our lives."* (Gramlich et al. 2002, 120)

Positive models of new inclusive research will still challenge all of us to think afresh about what social research actually is, about identity and about the outcomes and impact of such research. There are many questions that we are all still pursuing in this field. However, maybe some of the hallmarks of doing inclusive research identified in this chapter will help us to look at our practices with a critical reflective gaze, drawing not just on the critiques of traditional social research, but directly on the insights and analysis of inclusive research. It is hoped that this chapter has contributed to opening up those reflections.

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Inklusive Forschung stellt einen Ansatz dar, in dem Menschen mit Lernschwierigkeiten über den gesamten Forschungsprozess hinweg eine aktiv gestaltende Rolle einnehmen. Sie verkörpert somit eine *gemeinsame* Forschung von Menschen mit und ohne akademischen Bildungshintergrund. Während sich dieser Forschungsansatz in den letzten drei Jahrzehnten in vielen englischsprachigen Ländern zunehmend etabliert hat, begann ein vergleichbarer Prozess im deutschsprachigen Raum erst ab den frühen 2000er Jahren – hat aber seitdem eine interessante Entwicklung erfahren, die bislang kaum dokumentiert wurde. Dieses Buch hat daher das Ziel, einen Überblick zu aktuellen und bisherigen Bemühungen im Kontext von Inklusiver Forschung in Deutschland, Österreich und der Schweiz zu geben. Zudem werden hier die gesammelten (Forschungs-)Erfahrungen sowie die damit verbundenen Diskussionen und Herausforderungen kritisch reflektiert.
Zudem finden sich in dieser zweisprachigen HerausgeberInnenschaft Beiträge von VordenkerInnen aus der internationalen Forschungscommunity.

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